

Exhibit 1

**IN THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF UTAH**

Disability Law Center,

Plaintiff,

v.

Spencer Cox, *et al.*,

Defendants.

Case No. _____

DECLARATION OF CLARISSA C. KRIPKE, MD, FAAFP

I, Clarissa C. Kripke, hereby declare and state as follows:

1. My name is Clarissa C. Kripke.
2. I have actual knowledge of the matters stated herein. If called to testify in this matter, I would testify truthfully and based on my expert opinion.
3. My Curriculum Vitae is attached.

I. BACKGROUND AND QUALIFICATIONS

1. I received my medical degree from Temple University, School of Medicine in 1995.
2. I completed my residency in Family Medicine at Fairfax Family Practice in Fairfax, VA in 1998.
3. In 1999, I joined the clinical faculty at University of California, San Francisco (“UCSF”).

4. I am currently a Clinical Professor of Family and Community Medicine and the Director of Developmental Primary Care at UCSF.¹

5. As Director of the Developmental Primary Care practice, I developed a health services delivery model for adults with developmental disabilities who moved from institutions to the community or who are at risk of institutionalization. I provide home-based, primary care to medically fragile and behaviorally complex youth and adults with developmental disabilities in an innovative, interprofessional, home-based service delivery model. Through eight Professional Services Agreements, I serve as Medical Director of 25 community care homes for people with skilled nursing and psychiatric needs such as chronic ventilator use, suprapubic catheter care, enteral feeding, unstable seizure disorders, psychosis, aggression, self-injury and more. The model of care has been replicated across California.

6. In addition to my clinical practice, I have written and taught on issues involving people with intellectual and developmental disabilities, neurodevelopmental disorders, autism, and youth with special health care needs.²

¹ The views expressed here are mine and are not representative of the university in which I am affiliated.

² For example, some recent invited presentations on this include, Tips for Caring for People with Developmental Disabilities, Zoom Lecture at Hawai'i Pacific University Doctor of Physical Therapy Program in the Graduate College of Health & Sciences (2024) and Understanding Aggression and Self Injury, Update for Health Professionals in Developmental Disabilities, Webinar at University of California San Francisco (2023). Recent and forthcoming publications include: Emily Johnson & Clarissa Kripke, *Caring for Adults with Intellectual Disabilities in the Community*, 111 Am. Fam. Physician 267 (2025) and Kelly B. Beck et al. & Working to Increase Inclusivity in Research Ethics (WIRE) Consortium, *Guidelines for the Creation of Accessible*

7. I am also engaged in activities to support policy and system change to ensure that people with developmental disabilities can live successfully in their community and fully participate in all aspects of community life. A recent project included writing an implementation guide for Supported Decision-Making so that people with disabilities, including those for whom speech is not reliable, can direct their own medical care with support. The guide was based on focus groups with people with disabilities and caregivers as well as a series of meetings with thought leaders from organizations in California working to advance alternatives to conservatorship.

8. Furthermore, I provide advice, support and clinical perspectives to research teams working on improving health services delivery for people with disabilities. I am currently an academic partner on a five-year grant with the AASPIRE Community Based Participatory Research team to create tools to measure outcomes of services for adults on the autism spectrum.

Consent Materials and Procedures: Lessons from Research with Autistic People and People with Intellectual Disability, Autism in Adulthood (2025), advance online publication available at <https://doi.org/10.1089/aut.2024.0263>.

9. Recent publications include: *Healthcare Maintenance for Adults with Developmental Disabilities* (2024);³ *Primary Care for Adults with Developmental Disabilities* (2022);⁴ and *Developmental Disability Across the Lifespan* (2020).⁵

10. Finally, I am the parent of a 23-year-old who is nonspeaking and requires assistance with all basic activities of daily living. My child is also a straight A student at Arizona State University, and a leader in the self-advocacy movement.

II. SUMMARY OF EXPERT OPINIONS

11. Most medical professionals are not well equipped to accurately assess the capacity of people with intellectual disabilities.

12. There are many clinical definitions of “severe intellectual disability.” These definitions are not consistent with each other. One patient might receive different diagnoses depending on the classification scale used.

13. The new Utah law does not add any clarity about what it means by “severe intellectual disability.”

³ Geraldine Collins-Bride & Clarissa Kripke, *Healthcare Maintenance for Adults with Developmental Disability*, in *Clinical Guidelines for Advance Practice Nursing* (Yoonmee Joo et al. eds., 4th ed. 2024).

⁴ Geraldine Collins-Bride & Clarissa Kripke, *Primary Care for Adults with Developmental Disabilities*, in *Clinical Guidelines for Advanced Practice Nurses: An Interdisciplinary Approach* (Joanne Saxe & Geraldine Collins-Bride eds., 2022).

⁵ Clarissa Kripke, *Developmental Disability Across the Lifespan*, in *Family Medicine* (Paul Paulman et al. eds., 8th ed. 2020).

14. It is important for people with disabilities to be able to direct their own lives, and maximize their potential. Capacity is not a static measurement – it can only be assessed for a specific decision at a specific moment in time.

15. The new Utah law would cut people with disabilities off from important social connections. These help keep people safe.

16. Not everyone with significant cognitive or intellectual disabilities needs a guardian. There are almost always better ways than guardianship to provide even people with complex disabilities with support and protection.

III. EXPERT OPINIONS

A. The Medical Profession has Difficulty Diagnosing People with Intellectual Disabilities.

17. Clinicians often underestimate the abilities of patients with disabilities and doctors may misdiagnose someone because of bias, improper assessment tools, or lack of training. For example, in my experience, many clinicians are quick to assume that a patient has an intellectual or developmental disability simply because they do not speak, or have speech that is difficult to understand.

18. Many clinicians have received little or no training in working with patients with intellectual disabilities, or patients who may have limited or atypical communication. In these cases, they may make assumptions based on bias or stereotype about patients. For example, many clinicians do not even attempt to interview patients with disabilities. Instead, they communicate and interact with family or supporters who

attend appointments. Others speak to people with disabilities in simplistic terms or with a high-pitched voice one uses with children, rather than presuming competence and learning more about how to accommodate the person's communication and learning needs. This prevents clinicians from developing a real rapport and accurately assessing the patient.

19. Medical assessment tools are also imperfect. I know many people who were diagnosed with intellectual disabilities based on their scores on intelligence tests, but in fact have been able to demonstrate their capacity through other means. This is particularly common for patients with speech and motor challenges, as there are no intelligence tests that provide valid results for this population.

20. While medical innovations are challenging long held assumptions about the ability of people who cannot speak to understand and communicate, there is still more to uncover. With more experience or education, the types and complexity of information a person can receive and evaluate can improve. With illness, medications, or fear, it can decline.

B. There Are Many Definitions of “Severe Intellectual Disability” and Clinicians Do Not Have a Shared Understanding of the Term.

21. S.B. 199 now instructs doctors to diagnose someone as having a “severe intellectual disability.”

22. “Severe intellectual disability” is not a biologically defined diagnostic label.

23. The statute, as written, fails to provide medical professionals any additional principles to ascertain the meaning of “severe intellectual disability.” The law only provides that a person has a “severe intellectual disability” if a clinician diagnoses them as having a “severe intellectual disability.”

24. Medical clinicians will not share a common understanding of “severe intellectual disability,” because it is neither a universal medical diagnosis, nor sufficiently described by the statute.

25. The DSM-5 has one system of classifying intellectual disability across four categories: mild, moderate, severe, and profound. The DSM-5 scale focuses on the person’s daily skills and abilities.

26. The American Association on Intellectual and Developmental Disabilities has a different system of classifying intellectual disability, also across four categories: mild, moderate, severe, and profound. Unlike the DSM-5, this scale focuses on the level of support needed.

27. Many clinicians still rely solely on IQ test results. The previous edition of the DSM considered IQ scores of 20-35 to indicate “severe” intellectual disability, while lower scores indicated “profound” intellectual disability.

28. The chart on the next page, published by the NIH, shows the varied and inconsistent ways that “severe” intellectual disability can be classified.⁶

29. Many clinicians and hospitals classify the severity of intellectual disability based on a patient’s “mental age.” See Cleveland Clinic, *Intellectual Disability*, <https://my.clevelandclinic.org/health/diseases/25015-intellectual-disability-id> (last updated May 25, 2023).

30. The same person might be considered to have a “severe intellectual disability” on one of these scales but not the other. The law doesn’t tell clinicians how to decide what to do.

31. Not only are each of these scales different, but, for each of them, there is a degree of impairment greater than “severe.” It is not clear if the law is attempting to change the process only for people with “severe” disabilities but not those with “profound” disabilities.

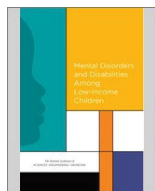
32. In sum, this means that four clinicians might have four different understandings of what “severe intellectual disability” means, and might not agree on whether or not it was appropriate to diagnose a particular patient with “severe intellectual disability.”

⁶ Comm. to Evaluate the Supplemental Sec. Income Disability Program for Children with Mental Disorders, *Clinical Characteristics of Intellectual Disabilities, in* Mental Disorders & Disabilities Among Low-Income Children 169, 171 (Thomas F. Boat & Joel T. Wu eds., Nat. Acads. Press 2015).

TABLE 9-1 Classifications of Intellectual Disability Severity

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)	AAIDD Criteria (severity classified on the basis of intensity of support needed)	SSI Listings Criteria (The SSI listings do not specify severity levels, but indicate different standards for meeting or equaling listing level severity.)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.	Intermittent support needed during transitions or periods of uncertainty.	IQ of 60 through 70 <i>and</i> a physical or other mental impairment imposing an additional and significant limitation of function
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.	Limited support needed in daily situations.	A valid verbal, performance, or full-scale IQ of 59 or less
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.	Extensive support needed for daily activities.	A valid verbal, performance, or full-scale IQ of 59 or less
Profound	1.5%	IQ <20	Requires 24-hour care.	Pervasive support needed for every aspect of daily routines.	A valid verbal, performance, or full-scale IQ of 59 or less

From: 9, Clinical Characteristics of Intellectual Disabilities



Mental Disorders and Disabilities Among Low-Income Children.
Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders; Board on the Health of Select Populations; Board on Children, Youth, and Families; Institute of Medicine; Division of Behavioral and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine; Boat TF, Wu JT, editors.
Washington (DC): National Academies Press (US); 2015 Oct 28.

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NCBI Bookshelf. A service of the National Library of Medicine, National Institutes of Health.

33. Even if medical providers could identify the meaning of “severe intellectual disability” in the abstract, S.B. 199 provides no diagnostic parameters for assessing an individual patient.

34. The law does not require specific assessment or a specific finding based on level of functioning that led to the diagnosis. This is particularly concerning given that a medical provider need not even *meet* the patient they are diagnosing, let alone have an ongoing treatment relationship, to make this diagnosis.⁷

35. In addition, the law does not require the clinician to explain the basis for their diagnosis, or make themselves available to the Court for questioning.

36. These problems mean that letters diagnosing a person with “severe intellectual disability” will be unreliable.

37. It is my opinion that many people with any level of cognitive disability, and many people with motor or speech disabilities but no cognitive disability at all, will be incorrectly categorized by clinicians as having severe intellectual disabilities.

38. Indeed, when faced with a family member pursuing guardianship, many clinicians will sign paperwork with little assessment thinking they are being helpful and without considering the unintended consequences and denial of rights.

⁷ But even if it did, most clinicians are not trained to do a comprehensive assessment. Those that are trained often use flawed assessment tools that produce invalid results.

C. S.B. 199’s Definition for “Severe Intellectual Disability” is Confusing.

39. Complicating matters even further, the legal definition for “severe intellectual disability” is confusing. If a clinician tries to read the law closely to understand what assessment they are trying to make, they will likely end up even more confused.

40. Part (i) of the definition requires that an individual be “incapacitated,” which under Utah law, requires a separate judicial determination.

41. Part (ii) then asks a clinician to determine whether a person has a “severe intellectual disability,” but in order to reach that opinion, a court must have determined that the individual was “incapacitated.” S.B. 199 seemingly invites a clinician to make a judicial determination about a person’s capacity—which a clinician cannot, of course, do.

D. It Is Important for People with Disabilities to be Able to Direct Their Own Lives.

42. Patients with disabilities are often excluded from conversations where important decisions are made.

43. Even if well-intentioned, family members of people with disabilities, service providers, public guardians, and funders have competing interests from the person with a disability.

44. A parent might, for example, feel that it would be better and more efficient for the parent to make medical decisions on behalf of an adult child, because they can

receive and process information more quickly. This denies people with disabilities the ability to provide input and to learn about their conditions, options, and opportunities.

45. Parents of young adults with disabilities are often very risk averse, and want to protect the person no matter what. Professional guardians are often even more risk averse, often to the detriment of the young adult's development and independence. The young adult with disabilities may want and need to develop their independence and try new things.

E. Intellectual Capacity is Not Fixed, as S.B. 199 Suggests.

46. The law suggests that intellectual capacity is a permanent trait or characteristic of a person. It is not.

47. Capacity has to be assessed for each decision to be made at each moment in time. People gain and lose capacity and can function very differently in different social or physical environments and with different accommodations, adaptive equipment, medical treatment, or support.

48. Function can improve or decline depending on the physical or social environment. For example, many people struggle to receive and evaluate information in a court or doctor's exam room. These are high stress environments where life-altering decisions including denial of rights are made. Those environments have lighting, sounds, and people who may make a person very uncomfortable. A patient who is assessed by a doctor in a bright, unfamiliar exam room might receive a diagnosis of a severe disability because they struggle to communicate in that context. But that same person, in a quiet,

comfortable setting with accommodations, might be able to receive and evaluate information and express preferences.

49. Function can also vary based on the type of decision. On the other hand, a person who can receive and evaluate information about one topic may struggle with another. Difficulty with one type does not mean that a person lacks capacity in all types. For example, a person who struggles to make one health care decision may be able to make another. Or a person who struggles with healthcare decisions may be able to make decisions about religious training, or who they trust to provide their support. Someone who needs assistance with personal care may be able to make decisions about education.

50. Even a person who has a significant cognitive impairment in some areas may be able to direct their lives, with support, in other areas.

51. If the person cannot take full responsibility for a decision, they may still have opinions or information to share which may be expressed verbally or nonverbally.

F. S.B. 199 would Give Guardians the Power to Cut off Social Connections that People with Disabilities Need to Thrive.

52. S.B. 199 empowers a guardian to limit an individual's association with family, friends and any other person they believe is harmful.

53. Friendships and relationships are a basic human need and critical for people with disabilities as much as they are for anyone else.

54. Not only are independent relationships crucial for social growth and connection, but they are also important for safety.

55. When someone who has control over all decisions also controls relationships, they can isolate the person from their community and from people who could notice there is a problem with the guardianship relationship and inform a judge that a change is needed.

56. Absolute power over another person can be corrupting and the law does not provide the person with the ability to maintain a strong circle of support outside of the guardianship relationship to make sure that the relationship remains healthy and safe.

57. It is important the people with disabilities have access to those who do not control funds or services so that they can report any harm or wrongdoing.

G. Individuals with a “Severe Intellectual Disability” Do Not Necessarily Need a Guardianship.

58. Guardianship denies the person the right to participate in meetings and conversations where important decisions that impact them are made.

59. People with significant intellectual disabilities who require support to manage their daily activities usually still have residual capacity to direct their services and their lives and to express their will and preferences.

60. The law presumes that people with severe intellectual disabilities require full guardianship. They do not.

61. Most of my patients have intellectual disabilities and require 24-hour care and total care for all of their activities of daily living, yet they do not have guardians.

62. There are many mechanisms to provide support to people with disabilities that are less restrictive than guardianship. For example, the government may appoint representative payees for social security benefits, Special Needs Trusts, Authorized Representatives for health care and ABLE Accounts, powers of attorney, and Supported Decisionmaking Agreements.

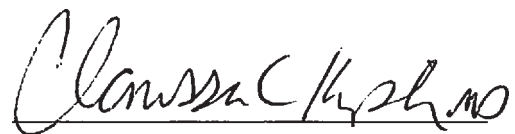
63. It is rare that there is a need that cannot be resolved in a less restrictive way.

64. Moreover, guardianship does not protect people with disabilities from abuse or neglect. In fact, it can make abuse or neglect more difficult to address since separating a person from their abuser requires going to court and proof.

III. CONCLUSION

65. I declare under penalty of perjury under the laws of the United States of America that the foregoing is true and correct.

Executed this 17th of April, 2025

A handwritten signature in black ink, appearing to read "Clarissa Kripke", written over a horizontal line.

Clarissa Kripke, M.D., F.A.A.F.P.